



Overcoming the Barriers to Palliative Care Referral for Patients With Advanced Heart Failure

Citation

Lindvall, Charlotta, Todd D. Hultman, and Vicki A. Jackson. 2014. "Overcoming the Barriers to Palliative Care Referral for Patients With Advanced Heart Failure." *Journal of the American Heart Association: Cardiovascular and Cerebrovascular Disease* 3 (1): e000742. doi:10.1161/JAHA.113.000742. <http://dx.doi.org/10.1161/JAHA.113.000742>.

Published Version

doi:10.1161/JAHA.113.000742

Permanent link

<http://nrs.harvard.edu/urn-3:HUL.InstRepos:12064381>

Terms of Use

This article was downloaded from Harvard University's DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at <http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA>

Share Your Story

The Harvard community has made this article openly available.
Please share how this access benefits you. [Submit a story](#).

[Accessibility](#)

Overcoming the Barriers to Palliative Care Referral for Patients With Advanced Heart Failure

Charlotta Lindvall, PhD, MD; Todd D. Hultman, PhD, ACNP; Vicki A. Jackson, MD, MPH

In the care of seriously ill patients, cardiologists and other physicians must have many skills to effectively help the patient and family manage the symptoms from the illness, cope with and understand the likely illness trajectory, and navigate complex medical decision making. Cardiologists routinely use these skills to effectively maximize the patient's quality of life. However, for those patients who have a severe symptom burden or more difficulty coping with the complexities of a serious illness, consultation by a palliative care clinician can be a valuable resource.

The Center to Advance Palliative Care defines subspecialty palliative care as follows: "Specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis or prognosis. The goal is to improve quality of life for both the patient and the family. Palliative care is delivered by a team of doctors, nurses, and other specialists who work with the patient's doctors to provide an extra layer of support." This differs from hospice, which is a type of medical care that is limited to patients who have a prognosis of less than 6 months and who have agreed to forgo any further curative treatment. Unlike hospice, palliative care is appropriate at any stage in a serious illness and can be provided together with curative treatment.

Until recently, most palliative care research has focused on patients with metastatic cancer. Randomized, controlled trials have shown a multitude of benefits, including improved quality of life and prolonged survival.^{1,2} Patients receiving palliative

care report lower rates of depression in the context of increased illness understanding, and prognostic awareness and they tend to elect less aggressive medical care at the end of life with longer enrollment in hospice and even longer survival. Interestingly, these benefits become apparent when palliative care consultation is provided alongside standard oncology care early in the disease process.

Palliative care is less established for heart failure patients, but studies show that this patient population may benefit as much from palliative care as cancer patients.^{3–5} Heart failure causes many different symptoms that adversely affect a patient's quality of life, such as fatigue, shortness of breath, anxiety, and depression.⁶ The illness trajectory is less predictable than for cancer, often making it more difficult for patients to navigate the illness and plan for the future. However, because life expectancy is unpredictably shortened after a heart failure diagnosis, identifying a patient's goals and values are as important. For example, a consequence of end-stage heart failure is increasingly frequent hospitalizations, which can become burdensome to patients and their families. Palliative care can help make sure that burden is balanced with the patient's overall goals.

Despite the potential benefits, palliative care specialists do not frequently participate in the care of patients with heart failure. The study by Kavalieratos et al.⁷ in this issue of the *Journal of the American Heart Association* explores barriers to palliative care referrals in heart failure. They conducted semistructured interviews with primary care, cardiology, and palliative care providers to assess their knowledge, attitudes, and perceptions of palliative care.

All participating clinicians endorsed palliative care involvement in the care of patients with heart failure. However, it was not clear that the providers had an accurate understanding of the domains of palliative care and how it differs from a hospice. In the study, nearly all primary care and cardiology providers were unable to distinguish palliative care from hospice or end-of-life care. Subjects also did not recognize that palliative care is not prognosis dependent and can be provided alongside life-prolonging therapy. Consequently, cardiology providers frequently identified the indication for palliative care referral as the "point at which you are unable to do more." The study also identified more basic referral

The opinions expressed in this article are not necessarily those of the editors or of the American Heart Association.

From the Massachusetts General Hospital (C.L., T.D.H., V.A.J.); Division of Palliative Care (C.L., T.D.H., V.A.J.); Department of Medicine (C.L., V.A.J.); Harvard Medical School (C.L., V.A.J.).

Correspondence to: Vicki A. Jackson, MD, MPH, Massachusetts General Hospital, 55 Fruit Street, Founders 600, Boston, MA 02114. E-mail: vjackson@partners.org

J Am Heart Assoc. 2014;3:e000742 doi: 10.1161/JAHA.113.000742.

© 2014 The Authors. Published on behalf of the American Heart Association, Inc., by Wiley Blackwell. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

barriers. For example, most nonpalliative providers did not know how to access palliative care, even though they worked at an academic center with an established palliative care service. The researchers used robust qualitative methods, but concluded that the findings should be confirmed by survey research on a national level. Although a larger sample of cardiologists would be useful, their findings are consistent with previous studies.⁸

The Kavalieratos et al. study⁷ is an important contribution to the literature because it clearly articulates common barriers to integration of palliative care into the care of patients with advanced heart failure. The researchers have given a road map for groups who are working to cultivate an approach where palliative care is integrated into heart failure clinical practice. The barriers identified include cardiology and primary care providers' lack of knowledge about the field of palliative care and methods to most effectively collaborate, the need to develop appropriate triggers for consultation, and discomfort with the moniker palliative care.

The barriers to palliative care involvement, as reported in the current study, were similar to those encountered by our group during implementation of quality improvement initiative in our system aimed at facilitating palliative care integration.⁹ We learned many lessons in this work and suggest several approaches to manage the barriers identified by the researchers in this helpful study.

1. Ease the referral process and give providers the language: Referring clinicians often worry that patients will fear they are "giving up" when palliative care consultation is recommended. We often guide our referring clinicians to introduce palliative care in the following way: "We have been managing your heart failure for some time now, and I want to make sure we are doing everything possible to help you do as well as you can. The palliative care team can make sure your symptoms are in good control and that you and your family are getting an extra layer of support."
2. Build a collaborative relationship and promote learning through joint patient visits: To build a truly collaborative relationship, it is important to promote bidirectional learning. We have found that joint visits can help achieve this goal. Cardiologists are able to gain knowledge about the components of the palliative care consultation. It is often surprising to referrers that much of an initial palliative care consultation is spent understanding the patient experience and helping him or her develop strategies to live more fully in the face of a serious illness, rather than planning for the patient's death. In these joint visits, palliative care providers can learn more about newer approaches to the management of heart failure and have a better understanding of why interventions such as a left ventricular assist device may or may not be offered to a

patient. Periodic joint patient visits also are beneficial for the patient who is able to see firsthand that the clinicians are part of a team and that palliative care does not mean that he or she is being abandoned by the cardiology team. This shared learning can also be expanded to other venues, such as grand rounds or clinical teaching conferences.

3. Automatic triggers facilitate palliative care involvement: Prognostication is very challenging, especially for illnesses with unpredictable trajectories such as heart failure. The providers in the Kavalieratos et al. study⁷ voiced concern about knowing when to refer patients to palliative care. The use of triggers for palliative care referral has successfully been used in other settings, including in the intensive care unit.¹⁰

Triggered referrals have the benefit of helping providers more objectively identify patients who may benefit from consultation, facilitate palliative care as part of routine care for patients with advanced heart failure, and set the stage for outcomes-based research. We suggest a clinical trigger for automatic palliative care consultation that is mutually agreed upon by cardiology and palliative care providers. Triggers are most effective when the criteria appear as obvious indicators for palliative care referral. In our institution, patients with class IV heart failure and comorbidities, such as renal failure, oxygen-dependent chronic obstructive pulmonary disease, dementia, and metastatic cancer, are triggered for automatic palliative care consultation. Once the patient is identified, the cardiologist or primary care physician is contacted to ensure that the patient is appropriate for a palliative care consultation.

4. Palliative care. . . what's in a name?: The name of palliative care is frequently identified as a barrier for referrals, as was found in the current study. Some even suggest that the name of the service should be changed. We believe that the apprehension surrounding the name is best addressed by giving healthcare providers language to introduce palliative care. When palliative care is introduced appropriately, 90% of Americans describe themselves as "very or somewhat likely" to consider palliative care for a loved one if they had a serious illness.⁸

In our experience, as clinicians become more familiar with the benefits of palliative care and have developed a genuinely collaborative model, the difficulties with naming become less pronounced. Palliative care can become part of the cardiology team just as the electrophysiologist who performs the role of ablation procedures.

The care of seriously ill patients with heart failure is complex, and referral to palliative care is another tool cardiologists have to improve the care these patients receive.

The Kavalieratos et al. study⁷ helps us to understand more deeply the barriers to palliative care referrals in this patient population. As light continues to be shed on these barriers, we can develop strategies to overcome them.

Disclosures

None.

References

1. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363:733–742.
2. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA. Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *J Am Med Assoc*. 2009;302:741–749.
3. Evangelista LS, Lombardo D, Malik S, Ballard-Hernandez J, Motie M, Liao S. Examining the effects of an outpatient palliative care consultation on symptom burden, depression, and quality of life in patients with symptomatic heart failure. *J Cardiac Fail*. 2012;18:894–899.
4. Rabow M, Kvale E, Barbour L, Cassel JB, Cohen S, Jackson V, Luhrs C, Nguyen V, Rinaldi S, Stevens D, Spragens L, Weissman D. Moving upstream: a review of the evidence of the impact of outpatients palliative care. *J Palliat Med*. 2013;16:1540–1549.
5. Schwarz ER, Baraghoush A, Morrissey RP, Shah AB, Shinde AM, Phan A, Bharadwaj P. Pilot study of palliative care consultation in patients with advanced heart failure referred for cardiac transplantation. *J Palliat Med*. 2012;15:12–15.
6. Blinderman CD, Homel P, Billings JA, Portenoy RK, Tennstedt SL. Symptom distress and quality of life in patients with advanced congestive heart failure. *J Pain Symptom Manage*. 2008;35:594–603.
7. Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, Abernathy AP, Weinberger M. “Not the ‘grim reaper service’: an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc*. 2014;3:e000544 doi:10.1161/JAHA.113.000544
8. 2011 Public opinion research on palliative care: a report based on research by public opinion strategies. New York, NY: Center to Advance Palliative Care; 2011. Available at: <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>. Accessed February 23, 2014.
9. Bernacki RE, Ko DN, Higgins P, Whitlock SN, Cullinan A, Wilson R, Jackson V, Dahlin C, Abraham J, Mort E, Scheer KN, Block S, Billings JA. Improving access to palliative care through an innovative quality improvement initiative: an opportunity for pay-for-performance. *J Palliat Med*. 2012;15:192–199.
10. Nelson JE, Curtis JR, Mulkerin C, Campbell M, Lustbader DR, Mosenthal AC, Puntillo K, Ray DE, Bassett R, Boss RD, Brasel KJ, Frontera JA, Hays RM, Weissman DE; Improving Palliative Care in the ICU (IPAL-ICU) Project Advisory Board. Choosing and using screening criteria for palliative care consultation in the ICU: a report from the Improving Palliative Care in the ICU (IPAL-ICU) Advisory Board. *Crit Care Med*. 2013;41:2318–2327.

Key Words: Editorials • health-related quality of life • heart failure • palliative care